



STATE OF WASHINGTON
DEPARTMENT OF HEALTH
Community and Family Health
Olympia, Washington 98504

April 13, 2005

TO: Washington State Board of Health members

FROM: Office of Maternal and Child Health, Genetic Services

**SUBJECT: PROGRESS REPORT: UNIVERSAL NEWBORN HEARING
SCREENING IN WASHINGTON**

This report is presented to the Washington State Board of Health in response to a request for an update on Universal Newborn Hearing Screening (UNHS) in the State of Washington. The report contains detailed information on:

- Current hearing screening rates in Washington
- Collaborative efforts to support voluntarily UNHS
- Status of the Department of Health's (DOH) system for monitoring, assisting, and evaluating UNHS programs
- Ongoing issues related to UNHS in Washington

The board has addressed the topic of newborn hearing screening on multiple occasions. In October 2001 the board and the Department of Health convened an advisory group to review the disorders included in the mandated newborn screening battery. In May 2002 the advisory group recommended that the board add newborn hearing screening. In October 2003 the board decided to wait to determine whether universal newborn hearing screening could be achieved voluntarily. At that time, the board made a commitment to ask the Department of Health to report back on the effectiveness of this approach within a year.

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Universal Newborn Hearing Screening in Washington State

April 2005

Executive Summary

Each year, nearly 80,000 infants are born in Washington. According to national estimates, 80-239 infants are expected to be born deaf or hard of hearing in this state. Without early identification and intervention services by six months of age, infants who are deaf or hard of hearing may suffer delays in language development, leading to permanent cognitive and social delays.

Early identification of infants with hearing loss begins at birthing hospitals with newborn hearing screening. Approximately 78,000 (98 percent) of infants in Washington are born in hospitals. According to annual Department of Health (DOH) surveys, Washington hospitals reported an increase in the statewide hearing screen rate from 62 percent in 2002 to 81 percent in 2003. The estimated statewide hearing screen rate for 2004 is 85 percent, which was less than the expected 90 percent, forecast in 2003. One reason for this difference was delays in hospital implementation of Universal Newborn Hearing Screening (UNHS) programs. For 2005, DOH anticipates that the statewide screen rate will be 95 percent. To obtain this rate, additional work will be needed to identify the obstacles UNHS programs face in screening every child and how to overcome them. Of the nearly 15 percent of infants born at hospitals who did not receive a hearing screen in 2004, 12-35 are expected to have hearing loss. The economic cost of failing to identify infants who are deaf or hard of hearing and enroll them in intervention services is not well established. However, such infants who are at increased risk to have language, cognitive, and social delay and may require additional services and support throughout their lives.

The collaborative efforts to support voluntary UNHS continue to improve hospital-based programs around the state. In 2003, 50 of 72 birthing hospitals reported having UNHS programs. At the end of 2004, 66 of the 68 birthing hospitals had programs. It is anticipated that all Washington birthing hospitals will have implemented UNHS programs by the end of 2005.

Department of Health's tracking and surveillance system, known as the Early Hearing-loss Detection, Diagnosis, and Intervention (EHDDI) system, follows infants born in Washington so they receive a hearing screen by one month of age and diagnostic evaluation, if needed, by three months of age. The department is currently receiving newborn hearing screening results voluntarily from, and providing follow-up services for, 42 of the 66 hospital-based UNHS programs. In addition, 12 out of 17 pediatric audiology clinics are sending diagnostic information to DOH. By the end of 2005, Department of Health expects to be receiving hearing screen results from all hospital based UNHS programs and diagnostic information from all pediatric audiologists.

During the first nine months (Quarters 1-3) of 2004, 10,856 infants were followed by the department using the EHDDI tracking and surveillance system. Analysis of reported hearing screen data and follow-up outcomes for these infants indicate that >95 percent received a hearing screen. Through this system, DOH has confirmed the diagnosis of some degree of hearing loss in 14 of these infants. This prevalence is within the expected range for this population.

While statewide collaborative efforts to improve UNHS are currently functional, further analysis is needed to determine the effectiveness and sustainability of these voluntary programs. Topics requiring additional attention include: evaluating infants with unknown outcomes; providing follow-up services for at-risk infants; understanding variable allocation of hospital resources; organizing early-intervention services; assessing potential regulatory actions; and identifying sustainable funding options for effective hearing screening.

Background Information

Congenital hearing loss has a relatively high prevalence compared to other conditions screened for at birth such as Phenylketonuria (PKU), which occurs in 1 per 15,000 infants.ⁱ Nationally, it is estimated that one to three of every 1,000 infants are born deaf or hard of hearing.^{ii iii iv v} Approximately 80,000 infants are born each year in Washington.^{vi} Based on the national frequency of early hearing loss, it is expected that between 80 and 239 infants are born with hearing loss in Washington annually. Studies show that early identification of these infants and enrollment in intervention services by six months of age contributes to age-appropriate language and cognitive development.^{vii viii ix} Newborn hearing screening is the first step toward this early identification of infants. Without newborn hearing screening, the average age of identifying hearing loss is between 12 to 25 months of age.^x

Newborn hearing screening is typically performed at the hospital shortly after birth. The procedure may consist of Otoacoustic Emissions (a measure of middle ear function), Auditory Brainstem Response (a measure of the brain's response to sound), or a combination of both tests. Infants who do not pass the newborn hearing screen are referred to a pediatric audiologist to establish a diagnosis through a thorough physiologic and behavioral evaluation. For infants diagnosed with hearing-loss, there are multiple management and long-term intervention services to consider.

National recommendations set forth by the Joint Committee on Infant Hearing¹ in 2000 state (1) all newborns will be screened for hearing loss before one month of age, preferably before hospital discharge; (2) all infants who screen positive will have a diagnostic audiologic evaluation before three months of age; and, (3) all infants identified with a hearing loss will receive appropriate early intervention services before six months of age. These three goals are known as the 1-3-6 plan.^{xi}

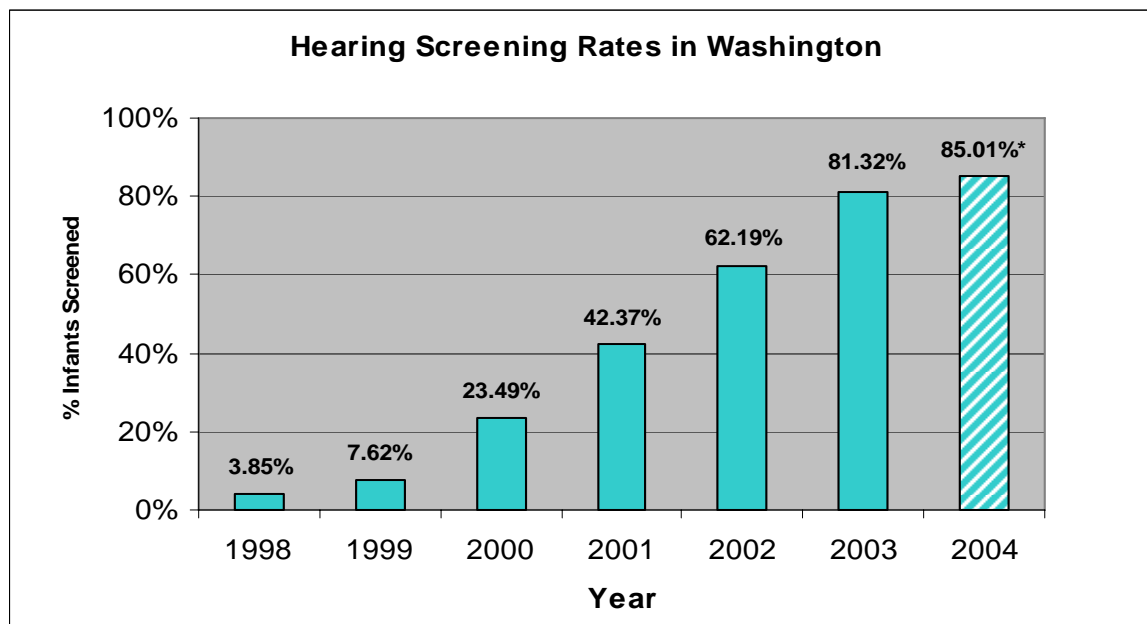
¹ The Joint Committee on Infant Hearing is composed of representatives from the American Academy of Audiology, the American Academy of Otolaryngology-Head and Neck Surgery, American Academy of Pediatrics, American Speech Language Hearing Association, Council on Education for the Deaf, and Directors of Speech and Hearing Programs in State Health and Welfare Agencies. The primary function of this committee is to make recommendations concerning the early identification of children with, or at-risk for hearing loss, as well as newborn hearing screening.

Current Hearing Screening Rates in Washington

In 2004, approximately 78,000 (98 percent) infants in Washington were born in birthing hospitals. Early identification of infants with hearing loss begins at birthing hospitals with newborn hearing screening. Hearing screening has been performed in Washington for many years. However, hospital hearing screen rates in Washington have only been collected by DOH annually since 1998. Hearing screening information was collected via phone and mail surveys from all birthing hospitals in Washington through 2003. The annual hearing screen rates and the estimated hearing screen rate for 2004 are presented in **Table 1**. These data reflect the total number of reported infants born at all Washington birthing hospitals who received a newborn hearing screen. The steady increase in hearing screen rates since 1998 is a product of both national and state efforts to identify all infants with hearing loss as soon as possible. Many of these efforts in Washington are described further in the following section.

In 2003, it was projected that the state hearing screen rate for 2004 would be >90 percent. Final hospital screen rates for 2004 are currently being collected and are not yet available. The best estimated screen rate for 2004 is 85 percent, significantly lower than expected. A possible reason for this difference includes unexpected delays in UNHS program implementation. Department of Health anticipates for 2005 that the statewide screen rate will be 95 percent. To obtain this rate, additional work will be needed to determine specific obstacles UNHS programs face in screening every child and how to overcome them.

Table 1



* Estimated hearing screen rate for 2004

Approximately 11,700 (15 percent) of infants born at hospitals in Washington did not receive a hearing screen in 2004. According to national estimates, 12-35 of these infants will have a hearing loss. The economic cost of failing to identify infants who are deaf or hard of hearing and enroll them in intervention services has not been well established. Such infants are at increased

risk for language, cognitive, and social delays and may require additional services and support throughout their lives.^{xii}

Collaborative Efforts Supporting UNHS in Washington

Hospital based Universal Newborn Hearing Screening (UNHS) programs seek to screen all infants born at their facility for hearing loss. The efforts to support and sustain these voluntary UNHS programs have been collaborative and multifaceted. Below are some of the groups in Washington that have been involved and their contributions to this goal.

Washington State Birthing Hospitals

Universal Newborn Hearing Screening programs are located within individual birthing hospitals. At the end of 2004, 66 of 68 Washington birthing hospitals have implemented UNHS programs. The remaining two hospitals without UNHS programs are currently working to develop hearing screening programs. The goal is for all hospitals to have a UNHS program by the end of 2005.

Hospital staff are responsible for nearly all aspects of UNHS program development and maintenance including: determining screening protocol; dealing with procedural issues; training screening staff; managing data; financing the program; obtaining and caring for screening equipment; and communicating with parents and care providers. In addition, 42 of the 66 UNHS programs are currently coordinating efforts with DOH to collect and report hearing screen results.

Washington State Hospital Association

The Washington State Hospital Association provides leadership, advocacy, and support to Washington hospitals. It has played an important role in encouraging hospitals to establish voluntary UNHS programs.

Children's Hospital and Regional Medical Center

Department of Health contracts with Children's Hospital and Regional Medical Center to provide ongoing technical assistance to hospitals that are interested in starting or maintaining a UNHS program. Children's Hospital and Regional Medical Center makes annual site visits to hospitals, conducts annual UNHS manager trainings, and develops and disseminates professional and parent education materials.

The Northwest Lions Foundation for Sight and Hearing

The Northwest Lions Foundation helps raise awareness of the importance of hearing screening through a public education campaign. They coordinate efforts with Children's Hospital and Regional Medical Center to provide additional technical and financial assistance to hospital UNHS programs. Hospitals demonstrating need have received direct funding from Northwest Lions Foundation to purchase hearing screening equipment and tracking software. Since 2002, Northwest Lions Foundation has partnered with DOH through a contract with MSR Northwest Inc. to specifically evaluate, recommend, and purchase hearing screening equipment and train hospital staff on its use for 18 Washington birthing hospitals that previously had no UNHS programs in place.

Audiologists

Audiologists provide the critical step to identifying those infants who are truly deaf or hard of hearing by performing diagnostic evaluation on infants who do not pass their hearing screen. Audiologists also assist the department in reviewing proper protocol in hearing screening and diagnostic evaluation, further outlined in **Appendix A** and **Appendix B**. Finally, audiologists are currently working with DOH to collect and report diagnostic results through a secure Web-based extension of the department's tracking and surveillance system.

The Department of Health

Department of Health established the Early Hearing Loss Detection, Diagnosis, and Intervention EHDDI) Program to help coordinate a statewide effort to improve and support screening, diagnostic, and early intervention services for infants born with hearing loss or increased risk for late onset hearing loss in childhood. Department of Health has also worked with government and private partners such as Department of Social and Health Services, and the Office of the Deaf and Hard of Hearing. And the department has developed a system — known as the EHDDI tracking and surveillance system — that follows infants from hearing screening through diagnostic evaluation. This system is discussed in further detail in the next section.

Status of DOH's System for Monitoring, Assisting, and Evaluating UNHS

In 2000, DOH received a Cooperative Agreement from Center for Disease Control and Prevention as well as a grant from Health Resources and Services Administration to establish the EHDDI program. Department of Health also received general fund state dollars for 2003-2005 to assist with program development. The goals of this program are consistent with the national 1-3-6 plan, which states that all newborns be screened for hearing loss before one month of age, all infants who screen positive have a diagnostic audiologic evaluation before three months of age, and all infants identified with a hearing loss receive appropriate early intervention services before six months of age. Ultimately, the EHDDI program aims to improve and support screening, diagnostic, and early-intervention services for infants born with hearing loss or increased risk for late onset hearing loss in childhood.

In the past five years, one of the accomplishments of the EHDDI program has been to develop a tracking and surveillance system. This system supports hospital based UNHS programs by (1) monitoring whether every infant receives a hearing screen; (2) assisting in making recommendations for timely follow-up care through diagnostic evaluation; and, (3) providing quality assessment and control through regular hospital and state-wide data analysis.

Monitoring Whether Every Infant Receives a Hearing Screen

This system compares live birth records with hearing screen results to monitor whether every child has received a hearing screen. Results of this comparison for the first three quarters (Q1-Q3) of 2004 (January through September) are shown in **Table 2**. Through the system, patients who did not receive a hearing screen are identified and follow-up actions are initiated to help ensure they receive a hearing screen by one month of age.

Table 2

Infant Hearing Screen Records 2004 (Q1-Q3) (a)		
Infants with a Hearing Screen Record (b)	10,401	95.81%
Infants without a Hearing Screen Record (c)	431	3.97%
Infants refused (d)	24	<1%
Total Live Births (e)	10,856	100%

(a) Q1-Q3 refers to the period spanning January through September of 2004

(b) Hearing screen record was reported via the revised blood spot card

(c) Infants without record were either missed or results were not reported

(d) Parental refusal for hearing screening indicated on revised blood spot card

(e) Total live births excludes infants who expired at or shortly after birth

Assisting in Appropriate and Timely Follow-up Care

Reported hearing screen results generate a series of appropriate follow-up actions to assure that timely follow-up care is provided through diagnostic evaluation. Hearing screen results and recommendations for additional hearing screening or evaluation are shared with the infant's primary care provider via letters, faxes, and phone calls carried out by the EHDDI program. The follow-up outcomes for the system are detailed in **Table 3**. For infants referred for additional audiological evaluation, eight out of 17 audiology clinics reported diagnostic information through a secure Web-based extension of the system. The available diagnostic outcomes for infants who did not pass their hearing screen and were referred for additional audiologic evaluation are reported in **Table 4**.

Based on the national incidence of early hearing loss of 1-3/1000 born deaf or hard of hearing, between 11 and 32 patients of the 10,856 patients followed by the EHDDI program during Q1-Q3 of 2004 are expected to have early hearing-loss. The DOH EHDDI program identified 14 patients with confirmed hearing loss, which is within this expected range.

Table 3

Follow-up Outcomes 2004 (Q1-Q3)		
Definition of Outcome	Number of Infants	Percent of Infants
Infant passed hearing screen	10,154	93.53%
Care provider shared recommendations for additional evaluation with infant's parents	326	3.00%
Infant was lost to follow-up efforts(a)	110	1%
Case is currently on-going	88	<1%
Infant was referred to an audiologist for further evaluation because of failed hearing screen(s)(b)	87	<1%
Infant's parents refused further hearing evaluation	38	<1%
Infant was referred to an audiologist for further evaluation because of reported risk factors on modified blood spot card(c)	34	<1%
Infant has moved out of Washington State	15	<1%
Care provider refused to share information with infant's parents	4	<1%
TOTAL	10,856	100%

(a) Status of infant is considered 'lost', either because DOH could not identify current care provider or provider could not contact infant's parents

(b) The Follow-up Outcomes for these infants are reported in **Table 4**

(c) See **Table 5** for definition of risk factors reported on the modified blood spot card

Table 4

Diagnostic Outcomes for Referred Patients 2004 (Q1-Q3)*		
Definition of Final Disposition	Number of Infants	Percent of Infants
Patient was found to have normal hearing	35	40.22%
Patient did not go to appointment	25	28.73%
Hearing-loss was confirmed	14	16.09%
Outcome is unknown	10	11.49%
Patient's evaluation is currently in-progress	3	3.45%
TOTAL	87	100%

* Diagnostic outcomes were gathered through the web-based reporting system as well as phone calls made by EHDDI staff

In addition to infants born deaf or hard of hearing, the EHDDI program follows infants at risk for developing late onset or progressive hearing loss. Specifically, the system identifies these infants when any of four risk factors are reported. See **Table 5** for definitions of these risk factors. Follow-up efforts carried out by the EHDDI program encourage care providers to refer these infants to an audiologist at six months of age for evaluation. Of the 10,856 patients followed during Q1-Q3 of 2004, 159 (1.5 percent) patients were identified as having at least one risk factor. The EHDDI program successfully informed the patient's care providers of the need for additional audiologic evaluation in 141 (89 percent) of these cases.

Table 5

Risk Factors for Early Hearing-Loss	
Risk Factor	Definition
Syndromic Stigmata	<i>Stigmata or other finding associated with a syndrome known to include sensorineural and/or conductive hearing-loss</i>
Family History	<i>A family history of permanent childhood sensorineural hearing-loss</i>
Craniofacial Anomalies	<i>Morphological abnormalities of the pinna and ear canal</i>
Maternal Illness	<i>In-utero infections such as cytomegalovirus, herpes, toxoplasmosis, or rubella</i>

Providing Quality Assessment and Control

The EHDDI program assists statewide UNHS efforts by providing hospitals with regular reports to assist in program performance evaluation. This evaluation is particularly important given the wide variety of UNHS program protocols in Washington. In addition, the EHDDI program undertakes routine internal evaluation to ensure the provision of an effective system. This is accomplished through, but not limited to, regular assessment of data collection methods, protocol revisions, technical upgrades, and data analysis.

Ongoing Issues Related to UNHS in Washington

Evaluating Infants with Unknown Outcomes

Evaluating infants with unknown outcomes is an important part of ensuring all infants receive appropriate care. Of particular concern is the number of infants who are missed or do not pass their hearing screen and never return for additional evaluation. Further analysis is needed to identify solutions for patients whose outcomes are unknown.

Providing Follow-up Services for at risk Infants

A national goal is identifying and providing follow-up services for infants at risk to develop progressive or late onset hearing loss in childhood. Given the limited resources available to conduct follow-up services, additional evaluation is needed to determine the most effective way to achieve this goal. Through a national research grant the University of Washington and Children's Hospital and Regional Medical Center, in collaboration with the DOH, are working to improve the accuracy of identifying and defining the overall effectiveness of following these infants at high risk for hearing loss.

Variable Allocation of Hospital Resources

Hospitals allocate resources for their UNHS programs in varying ways and amounts, inevitably affecting program quality. For example, there is wide variety in the training and background of screening staff hospitals use — from trained audiologists, to volunteers, to outsourced private contractors. Some hospitals reporting hearing screen results to DOH are relying on the EHDDI program to provide follow-up services while other hospitals provide these services alongside the department's efforts, at times creating redundant work loads. A better understanding of how hospitals allocate resources to UNHS programs is needed to assess program effectiveness, and possible options for sharing resources.

Organizing Early Intervention Services

The ultimate goal of UNHS programs and early diagnosis is to ensure infants who are deaf or hard of hearing receive timely intervention services and management to prevent delays in language and cognitive development. Currently, there is no statewide system to ensure infants receive intervention services following diagnosis. However, government and community partners from around the state continue to develop and promote appropriate intervention services and support for infants who are deaf or hard of hearing and their families. For example, the Department of Health and Washington Sensory Disabilities Services have been working together to implement a training plan for early intervention service providers. Future goals include ongoing outreach and education for early intervention service providers.

Assessing Potential Regulatory Actions

In October, 2001, the State Board of Health and the Department of Health convened an advisory group to review the disorders included in the mandated newborn screening battery. Their work concluded in May, 2002 with a recommendation that the board add newborn hearing screening. In October 2003, the board decided to wait to determine whether universal newborn hearing screening could be achieved through a voluntary system. The board made a commitment to ask DOH to report back on the effectiveness of this approach within a year. While the department received funding necessary to conduct surveillance and tracking, no funds were appropriated to Department of Social and Health Services or Medicaid to enable payment to hospitals for performing hearing screening.

Identifying Sustainable Funding Options for Newborn Hearing Screening

Limited financial resources allocated for hospital UNHS programs impact many aspects of newborn hearing screening including: access to care, quality of screening, and number of infants with unknown outcomes. Likewise, the DOH EHDDI program and the services it provides is currently funded through August and September, 2005 by HRSA and CDC grants, respectively. The program expects to receive general state funds through June of 2005. The application process for a new three year CDC grant (ending 2008) and a new HRSA grant is currently under way. Maintaining and improving the hospital and public health roles in providing successful hearing screening services in Washington will rely on identifying sustainable resources.

Additional Resources

Alexander Graham Bell Association for the Deaf and Hard of Hearing (AGBell): AGBell is an international membership organization and resource center on hearing loss and spoken language approaches and related issues. AGBell publishes and distributes books, brochures, instructional materials, videos, CDs, and audiocassettes related to hearing loss and provides financial aid for mainstreamed, auditory-based education opportunities.

www.agbell.org

American Academy of Audiology (AAA): is a professional organization dedicated to providing quality hearing care to the public. They provide consumer and professional resources related to hearing care. **www.audiology.org**

American Academy of Pediatrics (AAP): Provides information, alerts, and resources related to the physical, mental, and social health of infants, children, adolescents, and young adults. *Pediatrics* is an online publication of the American Academy of Pediatrics journal. The following is an article from one of their publications: *Universal Newborn Hearing Screenings: A Three Year Experience*. **www.aap.org**

American Speech-Language-Hearing Association (ASHA): Provides news, a resource center, and continuing education in the human communication field. **www.asha.org**

Boys Town National Research Hospital The below website was developed by Audiologists, Speech-Language Pathologists, Teachers of the Deaf, Geneticists, Doctors and Parents of Deaf and Hard of Hearing Children at the. This site includes information about infant hearing loss, how the ear works, family issues and some available intervention options. **www.babyhearing.org**

Centers for Disease Control & Prevention (CDC) Early Hearing-loss Detection and Intervention (EHDI) Program: Promotes helping children to develop and reach their full potential, through early hearing-loss detection and intervention. Collaborates with federal, national, and state agencies and organizations in assisting states and territories to develop and implement EHDI programs. **www.cdc.gov/ncbddd/ehdi**

Children's Hospital & Regional Medical Center (CHRMC): offers programs, lectures, and workshops focusing on audiology, hearing screening technology, communication skills, and hearing loss in children. **www.newborn-hearing-screening.org**

Health Resource Services Administration (HRSA) Maternal and Child Health Bureau: A federal agency that administers the Universal Newborn Hearing Screening program, which awards grants to states. **<http://mchb.hrsa.gov/programs/genetics/hearingscreen>**

March of Dimes Washington State Chapter: The March of Dimes Birth Defects Foundation works to improve the health of babies by preventing birth defects and infant mortality. They do this by funding programs of community services, advocacy, research, and education. **www.marchofdimes.com/washington**

National Center for Hearing Assessment and Management (NCHAM): The goal of the National Center for Hearing Assessment and Management at Utah State University is to ensure that all infants (newborns) and toddlers with hearing loss are identified as early as possible and provided with timely and appropriate audiological, educational, and medical intervention. **www.infanthearing.org**

Washington Sensory Disabilities Services (WSDS): provides information, training, technical assistance, and resources to families and educators statewide regarding individuals from birth to 21 years of age with sensory disabilities - students who are deaf, hard of hearing, visually impaired, blind, or deaf-blind. **www.wsdsonline.org**

Washington State Department of Social and Health Services (DSHS) Infant Toddler Early Intervention Program (ITEIP): Early intervention in Washington State is a collection of services families may need for their infants or toddlers with disabilities. Services include workshops, conferences, and information on infant/toddler development.

Family Resource Coordinators (FRCs) offer assistance to families with children who are deaf or hard of hearing. www1.dshs.wa.gov/iteip

Washington State Office of the Deaf and Hard of Hearing (ODHH): Provides services to the deaf, hard of hearing and deaf-blind communities throughout Washington State. ODHH contracts with six community service centers located in Seattle, Tacoma, Vancouver, Pasco, Spokane, and Bellingham to provide communication access advocacy, sign language interpreter information, workshops, information and referral, counseling, outreach and independent living support services to clients and their families. <http://www1.dshs.wa.gov/hrsa/odhh>

ⁱ Office of Newborn Screening, Washington State Department of Health, updated 02/25/2005, accessed 03/23/2005, www.doh.wa.gov/nbs

ⁱⁱ Northern, J., Downs, M. 1994. Universal screening for infant hearing impairment: Necessary, beneficial, and justifiable. *Audiology Today*, 1994; 6:10-13.

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^{iv} Mason, J., Herrmann, K. Universal infant hearing screening by automated auditory brainstem response measurement. *Pediatrics*, 1998; 101: 221-228.

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^x Yoshinaga-Itano C, From Screening to Early Identification and Intervention: Discovering Predictors to Successful Outcomes for Children with Significant Hearing Loss. *J Deaf Stud Deaf Educ*. 2003; 8(1):11-30.

^{xi} Joint Committee on Infant Hearing. Joint Committee on Infant Hearing Year 2000 Position Statement: Principles and Guidelines for Early Hearing Detection and Intervention Programs. *Pediatrics* 2000; 106(4):798-817.

^{xii} Karl White, Cost Efficiency of Newborn Hearing Screening, National Center for Hearing Assessment and Management, updated 10/22/2005, accessed 03/23/2005, www.infanthearing.org/summary/index.html